

PGD, The Right to Choose, Disability and the New Zealand Organisation for Rare Disorders (NZORD).

Ruth Fitzgerald

University of Otago, New Zealand

ruth.fitzgerald@stonebow.otago.ac.nz

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Abstract: In New Zealand, the activist group NZORD has been a persuasive voice for wider public access to genetic testing technologies for children. Their authority has rested on expert self-taught genetic knowledge, able political networking, meticulous public document preparation and the explicit public articulation of their children's suffering. This experiential authority has trumped alternative voices of experience (ie disability activist groups) wishing to restrict services such as pre-implantation genetic diagnosis (PGD). However, interviews with individual NZORD members at the time of the group's political lobbying revealed complex and contradictory understandings of PGD, its use within their families, its implications for personhood and the relationship between genetic difference and disability such that individuals were often unable to imagine its use for their own families. In such cases, 'the right to choose' was seen as the overarching moral principle to accommodate such dissonance. This paper sketches the New Zealand cultural background of 'the right to choose' and ponders whether a group identity such NZORD based on networked individualism represents a moral community in public decision making around PGD.

“We should not be content [*to study*] morality [*as*] an individual process of consciousness, of enacting ethical principles.... It is not sufficient to see that ethics are strongly influenced by necessity and power politics ... we need not fear that ... including ethics will moralize our theoretical concepts in a way that would make them useless. We will, however, need to shift from [*the study of*] moral systems to [*the study of*] virtuous action.” Thomas Widlok (2004:58)

Introduction

This paper is a reflection upon the discordance in public and private moral worlds for activist members of the New Zealand Organisation for Rare Disorders (NZORD) who as they spoke to me about their efforts to ensure public access to Preimplantation Genetic Diagnosis technology (PGD), sometimes indicated that, for themselves, they would not consider taking up the technology. I now retrace the complex lines of entanglement in our conversations between notions of disability, illness, and the moral value of the right to choose in an attempt to think through the variety of virtuous pathways the members followed in their personal decisions over PGD. In doing so, I follow Thomas Widlok’s (2004) approach to the anthropological study of virtue by tracking the varied paths of virtuous actions rather than cataloguing or describing dissonance and incompatibility within moral systems..

First, to provide some background information, NZORD itself is an umbrella group working on behalf of a wide variety of named disorder groups. NZORD members are an excellent example of the enactment of biological citizenship (Heath et al 2004; Petryna 2002) as in joining together they create a significant force to be reckoned with in the New Zealand health care system (which operates in a modified welfare state model of both private and state funded care). Their particular advantage arises because in New Zealand, state funded health care is distributed on a modified population based formula. This arrangement would otherwise disadvantage NZORD members for whom the great rarity of their conditions may cause them to be one of only two or three sufferers in the entire country.

Most members are very familiar with the process of genetic testing and many have lived through the development of an array testing techniques. These have

included procedures as invasive as the surgical biopsy of fetal tissue in utero, chorionic villa sampling, amniocentesis, through to the now well established practice of PGD, as well as the everyday testing of young children from buccal mucosa swabs, or as neonates from cord blood sampling, and Guthrie testing. As such, they have an expertise in this area derived through the time depth of their experience, and a political presence on the topic - enacted through public appearances, conference attendance, ministerial briefings and public submission writing and have contributed to the development of a specific public moral orientation (as an organisation) that promotes the genetic testing of children and embryos authorised through appeals to women's 'right to choose'.

The complex routes by which NZORD members arrive at their specific ideas of virtuous action in relation to genetic testing while operating under the umbrella of the notion of choice as a moral good forms the basis of this talk.

Methods

In speaking to this topic I drawing on two field trips conducted in 2004 and 2005 resulting in extended interviews with 10 NZORD families. Interviews were generally conducted with both parents (by myself or graduate students) and analysed through a narrative analysis technique. Stories of disability and the genetic testing of children emerged in every interview.¹ The interviews themselves were arduous. On many occasions sick babies, adolescents and adults lay in rooms adjoining the place where I was speaking with their parents. For some parents, their child had already passed away and interviews were conducted around the memorabilia of their time on earth. On one occasion I sat in the sunshine of an outdoor garden and spoke to the parents in an alternating pattern, as they worked in a rotation to provide cares to their eldest child who lay grievously ill in their living room which had been converted into a home hospital with a bed and all the associated medical paraphernalia. These conditions were generally neither painfree nor negligible in their impact on daily living. In many cases, they shortened lifespans sometimes to a period as brief but

¹ Ethical Approval for this study was obtained from the Human Ethics Committee Category A of the University of Otago, Dunedin, New Zealand.

intensely cherished as only one or two years. On one occasion I listened to the story of a mother whose child had not survived its delivery.

NZORD members' opinions on 'disability'

Although rhetorically at odds with Disability (and Bioethics) community members who argued *against* the use of genetic testing, the relationship between NZORD members and disability activists was a far more complex mesh of involvement than any simple oppositional arrangement. Certainly, at various times in the texture of their lives, the weft thread of their deep engagement with biomedical science as hope for the 'cure' of disability ran *against* the identity and the activist goals of Disability workers to create a nondisabling social environment. However there were also more moments when the warp thread of living in the context of a chronic and disabling illness seemed to run closely parallel to the experience of Disability and the following section discusses these commonalities, and tension points.

The first point in common was the degree and scale of the constant accommodations and organising strategies which families engaged in to manage the activities of living with a child or children who are unwell. This is also reflected in accounts of living with disability (Read 2000). For instance, appointments would become confused, red tape was battled, visits were planned with the precision of a military campaign in terms of ensuring food supplies, back up medications, ease of access etc. One mother of a little girl remembered interacting frequently with government departments, a variety of therapists and social workers, doctors and the respite carer: "We had a list of the names of about 30 or 40 different people that were all involved in [my daughter's] care one way or the other and as I say it was a bit like managing a small company" on good days and on a bad day "an absolute nightmare". The pressures of constant organising often frayed the bonds of intimate partnerships eg as one mother commented: " a lot of people do have just one parent doing [all the nursing of the child] , but it is so hard, and you know, we've seen so many marriages break up and if one person's doing everything, the other one just going off to work every day and not understanding what's going on ... " The

resulting arrangement for this particular family became what might seem like another family's dream - working from home, owning a business, sharing the money earning, sharing looking after [the son] but the organisational toll on the couple was such that they viewed it as "we've been forced into that situation really", their thanks was reserved more for the serendipity of being qualified for jobs that allowed them this degree of flexibility. Another younger family with whom I spoke (and without such options) had travelled half way round the world to return to their New Zealand extended family to help them with what was to become a 24 hour roster of caring – husband and wife taking the daylight shift and grandfather (who slept all through the day) working the night shift, to ease their eldest son's cramps, change his clothing, provide feeding, liquids and medications through a tube throughout the day and night.

The second line of strong resemblance between NZORD member stories and broader accounts of disability experience was their shared focus on activism. One family for example contained a young adult child living with EB who required many painful hours of bandaging every day on excruciatingly blistered skin. The parents initially managed all of his nursing between them when he was small, but after many years, eventually tried to get some district nursing support to allow them two nights off nursing each week. To do this they "made a huge fuss and it went on for a whole year " but they eventually obtained a compromise from the local hospital which agreed to provide nursing relief *if* the cost of the bandages did not come from the hospital's budget. By then linking up with the Society of Dermatologists, the parents commenced the second stage of negotiations - this time with the national government - to allow bandages as a prescription item. The final result was a national exemption for people with EB to be allowed prescription bandages from a special budgetary allocation for rare cases – a trailblazing piece of citizen activism. In this case while the topic seemed mundane (securing a supply of bandages) the stakes were as high as living or dying. As the parents noted: " If we hadn't been able to do that, you know, we would have just gone under, [our child] wouldn't have survived...

This shared valuing of activism caused some NZORD members to be more sympathetic to the oppositional position to PGD from disability groups. One person spoke with admiration of the legacy of past disability activism— things such as disabled parking and smoother wheelchair access for public buildings - which members of the public now took for granted. Energetic activism for full inclusion in society was seen by some as “provocative” but in a good way for the ability to increase everyone’s acceptance of diversity within humanity and for establishing the “right to be here” – a point that was relevant to their own children. There were also recognitions that able bodied society needed an activist to “go overboard” to get the very smallest of concessions. The Director of NZORD certainly recognised the link when looking back on his struggle for full inclusion of his now adult children into kindergartens when they were tiny, by remarking casually: “We were living the social model of disability [at that time] but we didn’t know it”.

Points of strain however also emerged around the topic of disability – specifically the way in which opponents of genetic testing seemed to incorporate being disabled into part of their personal identity. For example John recounted a surprising and somewhat bruising interaction with an academic who, after listening to his public talk on genetic testing, argued “Don’t talk to me about preventing disability because if you do, it devalues me as a person!”, and then wheeled away in high dudgeon. To underscore their different views on this topic, NZORD members would casually reveal during interviews, elements of disability within their own life history - a brush with polio for example, or a problem with impaired vision, carrier status for haemophilia, a fully expressed form of genetic difference such as albinism or possible genetic difference such as narcolepsy. NZORD members refused to define their personas only in reference to these things and rejected a meaning of disability that equalled personal identity.

Instead, they often invoked a sliding scale of suffering to define degrees of disability to assess what might or might not be a moral authority for deciding whether to use PGD. Life experience was the cornerstone to this. For example, one mother noted: “and this guy who was blind (*a speaker at a disability seminar*)

had the audacity to say JUST because he was blind, that he didn't think anyone should be allowed to have genetic testing... he counted himself as disabled (*rising incredulity*) and argued you shouldn't stop people having that sort of a life (*laughter of disbelief*)... what right does he have (*to stop access to PGD*)? Blindness for this mother could hardly count as disability in comparison with the daily suffering in which her child had been placed. The Director of NZORD saw it as a situation where the 'hardline' disability activists (as he termed them) who opposed the introduction of PGD, held ideas that were "100% right from their own perspective, because they are usually much more ABLE disabled people, but either they don't know or are dismissive of the reality of the people who are really severely affected by these conditions." For John, the social model of disability and even the New Zealand government disability strategy has been noticeable for its silence in comment on the lives of people with severe and degenerative conditions. Different participants also pointed out to me that at many public meetings and seminars debating PGD, members of the audience who lived with mental health disabilities were often more supportive of NZORD's efforts to eliminate disabilities through recourse to biomedicine, frequently calling out from the audience for example to disagree with 'hardliner's' statements that people were "content" to be disabled.

NZORD members also had an overriding sense of disability as a passive situation whereas chronic illness was a medical condition demanding assertive action. John Forman noted that a total reliance on only the social model of disability in for example the field of education, caused some to say "don't worry about a diagnosis, because that will just 'label' them, just treat them as a person who is different and learn to value them." For John, this was hard to reconcile, for in his experience "if you get the diagnosis, you can give them treatment... " In his terms he compared it to fortifying flour with folate . "If you can about halve the amount of spina bifida that occurs by adding just a vitamin... why would we not do that?

Diagnosis could also unlock a flood of ancillary services and grants to assist with daily living. For example, one family had to wait until their boy was five to discover that his disorder (Fragile X) caused problems in walking. Up until this

moment they had watched for years (heart in mouth) as his increasingly unsteady gait left them wondering if he would descend their staircase either bottom or head first. Linking the problem of walking to a diagnosis allowed the family to obtain orthotic footwear designed specifically to steady his feet. This insistence on continuing searches for medical interventions and diagnoses was at the heart of the group's persistent endorsement of greater access to a wider array of genetic testing technologies for their children. This was linked to a strong faith in experimental biomedical science rather than any endorsement of the value or restorative powers of clinical medicine. The relationship of NZORD members to medicine of which I have written about elsewhere (Fitzgerald 2008) is in fact more complex and far more interesting and comes closest to Erving Goffman's (1963) limited insider appreciation of a cultural world that he terms 'the wise'. In this case it is the awareness of an insiders' view of medicine that it can harm as easily as it heals. This partial insider status arrived as a result of their often decades of immersion in the medical world in which within the very tiny and hyperspecialised field of their children's rare conditions, NZORD members become more expert than their New Zealand doctors. NZORD members were noticeable for their cautious deliberation over whether to seek medical intervention or not, for their stoic exposure to catastrophic medical misadventures and their philosophical responses to it.² Whenever I have discussed this aspect of their relationship with medicine, it is this quality of 'expert patienthood' (Lorber 1981, Stacey et al 2009) that most strikes a disability activist audience as familiar and forms a potential point of shared experience. Just as those with long term disability would do, NZORD members searched for the 'good doctor' - pliable, biddable and who could provide access to needed services when requested, who would work in partnership with patients and was prepared to admit that s/he didn't know the answer. In this sense the quality that drove public identities most apart between NZORD and the 'hardline' disability activists (different views on the incorporation of new

² To indicate the severity of some of these catastrophes, the baby of the mother to whom I alluded in the opening paragraphs with regard to a child who did not survive the delivery process, died not as a result of his genetically inherited condition (which was a very severe form of polycystic kidney disease) but rather because the little boy's spinal cord was accidentally severed during the delivery.

medical technology) was, in lived experience, a point containing many elements of mutual recognition. At this point, I wish to move towards a discussion of the NZORD members thinking around the role of PGD in a 'good' society.

Pathways to virtuous action for NZORD members thinking on PGD

Unlike, the formal position espoused by NZORD on access to PGD, only around half of the interviewees were fully prepared to contemplate PGD in their own families. The lines of differing personal responses did not fall as some might expect (or as the 'Disability hardliners' might predict) between those who had casually mentioned that they were 'disabled' and those who were not. For example, two members made explicit reference to their genetic difference and stated unequivocally that to consider that an embryo would be discarded for having a chromosomal arrangement (such as their own) was quite unthinkable although they endorsed the technique for certain 'other' conditions. A third member was adamant that to choose to terminate an embryo for a condition similar in effect to her disability was quite reasonable: "I mean I wouldn't feel outraged if someone decided not to have a child because it contained a [name deleted] gene. I'm me you know, and you're talking about someone who hasn't been born yet".

The organising principles guiding virtuous action around PGD appeared instead to consist of several trigger points, the resolution of which created different responses (all of which could be encompassed within the notion of the public defense of the 'right to choose'). For some participants, the most important decision points depended upon where one understood life and personhood to begin. (The options which participants were working with here included birth, part way through the pregnancy, conception and a type of 'premortal' life experience.) Depending upon how one resolved this question, a virtuous person could then from this basis chose a congruent pathway for further action.

For those who recognised human life as appearing somehow through a pregnancy, the value of PGD lay in avoiding the ethical dilemmas of terminations. Form was often the argument used to remove what had previously been

obstacles to terminations during pregnancy for some of the participants. For example, one mother spoke of embryos as 'just some cells in a petrie dish'. One father noted of the embryo that: "it has no little arms, no little legs" although he observed that arguments to destroy embryos were still difficult to articulate in public as they went against dominant ideologies of 'loving children no matter what'. However all participants who countenanced the use of PGD to select against certain embryos regarded the moment of birth as the time at which the principle that "one loves one's children 'no matter what' " would apply.

Another mother endorsed the use of PGD to select against certain degrees of chromosomal difference because of her understanding that personhood existed in a premortal form prior to conception. In this case, the use of PGD would allow her to ensure that her children arrived in a healthy body and no matter how many times a parent used the technique of PGD, the number of children allotted to them would still arrive subsequently. Virtuous action lay in making use of all the technologies available to oneself to allow the child to be born to good health.

A completely different pathway to virtuous action was described by two mothers who (while still defending the 'right to choose') considered that human life and more particularly their own child's life began at the moment of conception. For this reason PGD was not a suitable test to undertake. Reflecting on the still quite recent death of her child, one mother stated: " it should be that disability or serious illness is just a part of life, I mean death IS part of our life, and I would much rather see a cure than you know selecting children on the basis of whether they had the disease or not." She recalled how when she had become pregnant again, (just after her son had died); she had undergone chorionic villa sampling at that time although only for the purpose of "getting the paediatrician ready (ie better prepared) " for the next child and to know whether she should take additional nutritional supplements to help the child she was carrying. (In fact this new pregnancy had not been affected). Similar reasoning (and action) was followed by the mother whose sons had metachromatic leucodystrophy as she was able to research with her husband during that second pregnancy, the value

of bone marrow transplants for the child and in all ways, be prepared to actively treat him to assist his symptoms.

This mother was the one individual in the group who professed a strong Christian faith which was also a source of virtuous action. She spoke of her preferred pathway to decision making over PGD being for the individual to talk to God. "Was the technique of PGD simply doctors playing too far with science or was it God talking to us through science?" Her thoughts were experience rich in the knowledge that chronic illnesses put families through intense pressure and that some people dealt with stress in destructive ways. Not everyone survived the experience and not everyone sought God through it. But in her world, suffering served a purpose and simply the sense that an illness was going to cause a child a great deal of suffering and bother was not a reason to choose to terminate them via PGD. Even so, she agreed that PGD should be offered for other families.

For around half of the participants, virtuous action surrounding the uptake of PGD arose as a consequence of thorough reflections on the suffering which one's children would bear and one's duty as a parent to protect children from such suffering. Families following this pathway would take up a variety of testing technologies at various points in the pregnancy regardless of their awareness of the embryo or fetus as their living child. One mother pointed out: "I met a lot of families that have a child with an abnormality that you know was diagnosed at 18 weeks and they've decided to abort the child and they still go through as much grief if not more than someone who's lost a child full term...." Recognition of this pathway caused another woman to urge others to 'honour' the experiential knowledge which parents of sick children brought to their decision making. Regardless of the pain of the loss which it would cause, in these cases parents acted to avoid the 'obscenity' and the 'horrors' as they termed it of further suffering to subsequent children. An older mother of adult children said of them "they're still my children and I mean that unconditional love, but you know I couldn't honestly say that I wouldn't want them any other way - they miss out on so much...". Working through this line of action, parents chose PGD

in anticipation of what their future children would think of a life lived under such circumstances. Some mothers sought an answer through the entwined mesh of love, guilt and obedience that marks family life, to ask their surviving children if they would wish to be born with the disease or to have been tested.

Including children in the discussion of their family's use of genetic testing technologies was another frequently mentioned aspect of a virtuous path. One mother for example (much to the concern of attending physicians) brought her young son along to her amniocentesis with a small puzzle to keep him quiet. She felt that it was important he was included in the process and was well prepared in case the pregnancy was terminated. The Director of NZORD related how at certain conferences it was a pleasure for him to see children talking about their bone marrow donations to siblings saying "some of me is inside her – I gave her my bone marrow and made her better" and that he had met many families comprised of affected children, healthy children and children created through PGD and all of them were loved equally as well and all very knowledgeable of their situation.

The final point that many suggested was a necessary element of a virtuous path to the possible use of PGD was a careful inventory of the reasons why one might consider using the technology – particularly avoiding selfish reasons for its use – such as "losing this child will hurt me too much".

Conclusion: NZORD meanings of The Right to Choose in New Zealand

The discrepancy between the goals of public activism and personal beliefs for these parents are best understood as Widlock (2004) suggests by speaking of these variations as the 'is' and the 'oughts' of a moral landscape. The media hype and publicly organised debates around PGD which were prevalent at the time of these interviews portrayed a polarised field of extreme positions over 'designer babies'. Such accounts attempted to present the starkly divergent possible 'oughts' around genetic testing in New Zealand ie ought legislation be introduced to facilitate this technology or to stop it? In a similar manner, so does

the public position of NZORD and the 'hardline' Disability activists objections to it.

The conversations with the membership of NZORD presented in this paper on the other hand provide an array of what 'is' - those pathways to virtuous action that are derived from the experience of striving to achieve the 'good' in life under adverse circumstances and within complex human biographies and a specific political economy. While NZORD's reliance of the 'right to choose' harks back to uneasy relationships between feminist values and concepts of disability and disabled people (McLaughlin 2003; Earle 2002) the diverse virtuous actions taken on by its varied membership within this overarching position were in fact inclusive of the right to life at least for certain of its members.

In continuing to raise the provision of choice as a virtue, it seemed to the listener that NZORD families were looking backwards often through years of travail and questioning to find a telos for their suffering in the provision of choice for others. In this sense they were not prioritising a logic of choice over a logic of care in the sense in which Mol (2006) describes these contradictory regimes of thinking, nor indeed mistaking choice for a pseudo virtue as MacIntyre (1981) has suggested is the marker of contemporary philosophical life. Rather they seemed to be acting virtuously in the Aristotelian sense of living according to certain rules and notions of obligation which lead towards a recognised and shared endpoint or telos – in this case, the provision of the best parental care possible, fully cognisant of the responsibilities that such caregiving required. For NZORD members, this exercise of parental responsibilities was expressed (counter intuitively perhaps for some readers) through political activism to promote the provision of choice in the use of PGD – a choice that certain members of NZORD knew that they would never take up or which for others, had arrived far too late to be of any personal use.

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